

REVIEW

Transitioning adolescent and young adults with chronic disease and/or disabilities from paediatric to adult care services – an integrative review

Huaqiong Zhou, Pamela Roberts, Satvinder Dhaliwal and Phillip Della

Aims and objectives. This paper aims to provide an updated comprehensive review of the research-based evidence related to the transitions of care process for adolescents and young adults with chronic illness/disabilities since 2010.

Background. Transitioning adolescent and young adults with chronic disease and/or disabilities to adult care services is a complex process, which requires coordination and continuity of health care. The quality of the transition process not only impacts on special health care needs of the patients, but also their psychosocial development. Inconsistent evidence was found regarding the process of transitioning adolescent and young adults.

Design. An integrative review was conducted using a five-stage process: problem identification, literature search, data evaluation, data analysis and presentation.

Methods. A search was carried out using the EBSCOhost, Embase, MEDLINE, PsycINFO, and AustHealth, from 2010 to 31 October 2014. The key search terms were (adolescent or young adult) AND (chronic disease or long-term illness/conditions or disability) AND (transition to adult care or continuity of patient care or transfer or transition).

Results. A total of 5719 records were initially identified. After applying the inclusion criteria a final 61 studies were included. Six main categories derived from the data synthesis process are *Timing of transition; Perceptions of the transition; Preparation for the transition; Patients' outcomes post-transition; Barriers to the transition; and Facilitating factors to the transition.* A further 15 subcategories also surfaced.

Conclusions. In the last five years, there has been improvement in health outcomes of adolescent and young adults post-transition by applying a structured multidisciplinary transition programme, especially for patients with cystic fibrosis and diabetes. However, overall patients' outcomes after being transitioned to adult health care services, if recorded, have remained poor both physically and psychosocially. An accurate tracking mechanism needs to be established by stakeholders as a formal channel to monitor patients' outcomes post-transition.

What does this paper contribute to the wider global clinical community?

- Evidence of improvement in health outcomes of adolescent and young adults with chronic disease and/or disabilities post-transition by applying a structured multidisciplinary transition programme, especially for patients with cystic fibrosis and diabetes since 2010.
- The identification of 'readiness to transition' as a critical element to improve patient outcomes.
- The need to establish an accurate tracking mechanism to monitor patients' outcomes post-transition.

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Key words: adolescents, chronic illness and/or disabilities, integrative review, paediatric to adult care services, transitioning care, young adults

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Introduction

The need to provide transitioning care to adolescents and young adults was first recognised during the 1980s in the USA due to increased numbers of paediatric patients with chronic illnesses/disabilities surviving to adulthood (Blum 1991, Blum *et al.* 1993). Transitioning patients within and across health care facilities has been gradually conceded as a complex process rather than an event or a single step at a point in time (Department of Health Western Australia 2009, Gilliam *et al.* 2011, Stewart *et al.* 2014, Westwood *et al.* 2014). The transition of care process is, therefore, defined as 'a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location' (Coleman & Boulton 2003, p. 556). Experiences associated with transitioning adolescent and young adults not only impacts on their special health care needs, but also psychosocial development, including ability to consolidate identity, achieve independence and establish adult relationships (de Silva & Fishman 2014).

There are an estimated 4.5 million (18.4%) of youth aged 12–18 requiring special health care needs in the USA (McManus *et al.* 2013). Of these, it is reported only 40% of them receive transitional services to adult health care, work, and independence as per established national transition core outcomes (Department of Health Western Australia 2009, McManus *et al.* 2013). Additional research from the USA suggests delays in the transition of young adults with special care needs, approximately 445,000/year, results in these adults continuing to reside under paediatric health care services (Fortuna *et al.* 2012). In particular, Collins *et al.* (2012) and de Beaufort *et al.* (2010) found patients aged 16–17 years with chronic medical conditions remained predominantly under the care of paediatricians (70% of their visits); while patients aged 17–24 were continuing to be seen by a paediatrician for 16% to 36% of their visits (Heaton *et al.* 2013, Stewart *et al.* 2014).

The timing of the transition to the adult care services has always been the centre of debate. Late transition (>18 years old) can lead to poor patient outcomes mainly due to the late exposure to the adult care settings and lack of independence (van Staa *et al.* 2011b, Paul *et al.* 2013). Others argue that early transition could be associated with

increased risk of psychosocial issues (Helgeson *et al.* 2013). The ideal time to transit adolescent and young adult with chronic illnesses/disabilities may not be associated with chronological age, especially with patients who have complex health conditions (O'Sullivan-Oliveira *et al.* 2014, de Silva & Fishman 2014).

Patients often feel anxious and concerned at the thought of being transitioned to adult care services. Providing sufficient preparation prior to the transition is, therefore, critical (Fegran *et al.* 2014, de Montalembert & Guitton 2014). Regardless of this awareness, research suggests many patients were unsure of the process with only 21% of parents/primary carers reporting their child had discussions with the adult health care provider prior to the transition (McManus *et al.* 2013). Patients also reported that the transition was not carried out systematically due to what they believed was a lack of coordination (Bindels-de Heus *et al.* 2013).

Patients have also observed differences between the two care settings during the transition process (de Silva & Fishman 2014). Paediatric health care providers sometimes ignore the growing independence of adolescents. In contrast, adult care providers encourage adolescent patients to take responsibility for their health even though this may lead to neglect of physical, psychological and social development (Valenzuela *et al.* 2011, Hanna & Woodward 2013, Huang *et al.* 2014, de Silva & Fishman 2014). As a result, adolescents and young adults often feel lost in adult care services leading to lower rates of follow-up appointments, attendance and medication compliance (van Staa *et al.* 2011a).

A range of approaches and strategies (Kingsnorth *et al.* 2007, Crowley *et al.* 2011), especially structured transitioning programmes, have been developed and implemented to improve patients' health outcomes (Grant & Pan 2011, Chaudhary *et al.* 2013). Evidence on the effectiveness of these programmes is not conclusive, which may be due to wide variations in the structure and delivery of those programs (Doug *et al.* 2011, Hankins *et al.* 2012).

Aim

This paper aims to provide an updated comprehensive review of the research-based evidence related to the

transitions of the care process for adolescents and young adults with chronic illness/disabilities since 2010. The results of this review will recommend critical elements for developing transition programmes.

Methods

Design

The design is an integrative review, a method of research that appraises, analyses and integrates literature on a topic so that new frameworks and evaluations are generated (Torraco 2005). This methodology allows the inclusion of studies with diverse data collection methods (Whittemore & Knaf 2005). The PRISMA statement was also used, in combination with the integrative review, to structure the review, minimise analysis bias and systematically present findings.

Literature search strategies

This review was conducted to synthesise the research evidence from 2010 to 31 December 2014. Articles eligible for inclusion were those published in English with full-text access. Eligible studies were peer reviewed, with clear evidence of research methodology, including qualitative, quantitative, mixed methods and systematic reviews.

A search was carried out on the following databases: CINAHL, Embase, MEDLINE, PsycINFO and AustHealth. Database-specific subject headings and relevant text words were used. Search strategies contained terms related to (adolescent or young adult or adolescent* or teen*) and (chronic disease or long-term ill* or long-term condition* or chronic ill* or chronic condition* or disability or disabled children or disabled person) and (transition to adult care or continuity of patient care or transfer* or transition*).

Search outcomes

The combined database search generated a total of 5719 records, 120 duplicates were removed. Titles and abstracts were appraised to confirm those that fitted the review question ($n = 5491$ excluded). The remaining 108 records were reviewed against selection criteria. A further 47 records were excluded as conference abstracts (26), nonresearch paper (17), and nonmedical transition (4). A hand search of the reference lists was also conducted with no further results. A hand search of the reference lists was also conducted, and no additional studies were identified. A total of 61 studies were included. Figure 1 is a flowchart of the process of the study selection.

Data evaluation

The quality of included articles was appraised independently by the first author (HZ) who has more than 20 years of paediatric nursing experience, and the fourth author (PD), a professor of nursing. Meta-analysis of Statistics Assessment and Review Instrument (MAStARI) and Qualitative Assessment Review Instrument (QARI) were used to assess the methodological quality of the 61 studies (The Joanna Briggs Institute 2011). No studies were further excluded on the basis of quality assessment.

Data extraction and synthesis

Item-by-item comparison of extracted data enabled coding and grouping, which identified six main categories. All authors validated emerging patterns throughout the analysis process (Whittemore & Knaf 2005). The categories provided the framework to organise the literature and compare the studies systematically (Torraco 2005).

Results

Study demographics

Sixty-one studies were included (see Table 1), and the majority was conducted in the USA (31), followed by UK (7), Canada (7) and the Netherlands (6). The study designs employed included nonexperimental quantitative studies (35), qualitative design (15), mixed methods design (6), and systematic review (5). Of the 35 quantitative studies, the majority were conducted using survey. Semi-structured individual interviews and focus group were the primary data collection methods of the qualitative studies. The main focus of the studies included chronic illness/condition in general (24), disabilities (9), and diabetes (5).

Six categories emerged from the 61 studies: *timing of transition; perceptions of the transition; preparation for the transition; patients' outcomes post-transition; barriers to the transition; and facilitating factors to the transition*. The data analysis also identified a further 15 subcategories.

Category 1 Timing of transition

The category timing of transition (12/61 included studies) consisted of three subcategories: *timing to educate patients about transition process; the preferred timing to transit; and the age transitioned*.

Three studies explored the preferred timing to begin the education of paediatric patients with chronic illnesses/disabilities about the transition process. Two studies suggested the most appropriate time is early teens (11–12 years) or time of the diagnosis (10–14 years) (Price *et al.* 2011,

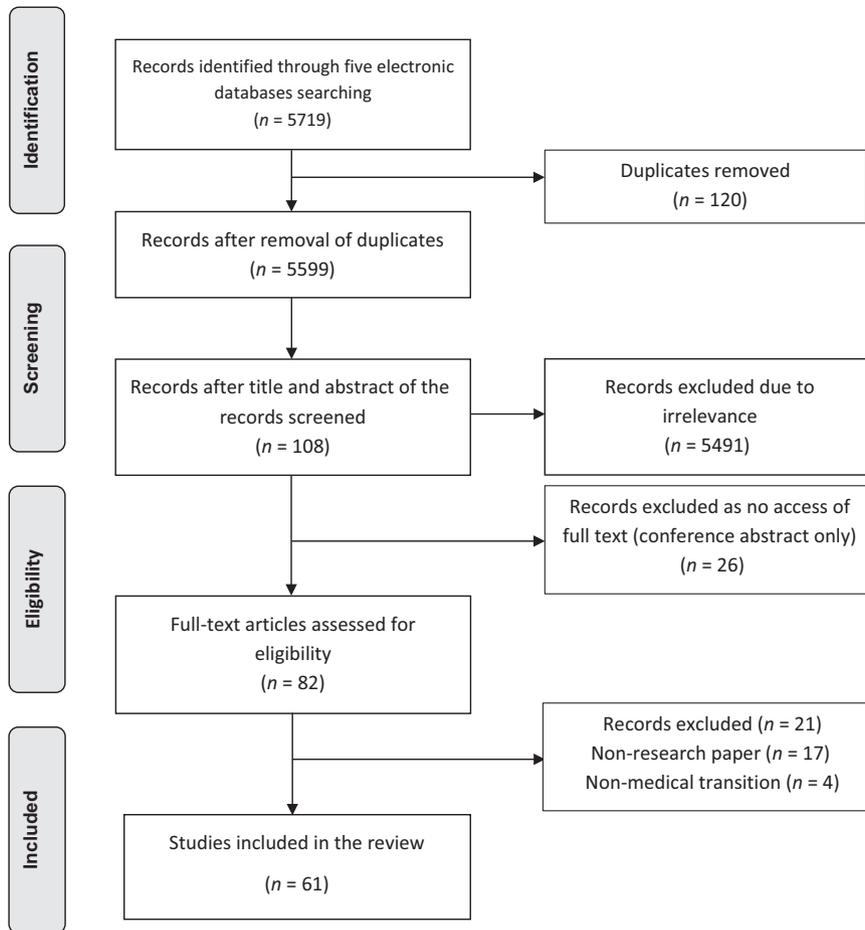


Figure 1 Flow chart for the search and study selection process (PRISMA).

de Silva & Fishman 2014); whereas Sebastian *et al.* (2012) argued 14 years or later.

Nine studies investigated the preferred timing of being transitioned to adult care services. Eight studies suggest that preferred timing relates to chronological age (mid teen – early twenties) (de Beaufort *et al.* 2010, Dowshen & D'Angelo 2011, Gilliam *et al.* 2011, Godbout *et al.* 2012, Sebastian *et al.* 2012, Fernandes *et al.* 2014, Rutishauser *et al.* 2014, de Silva & Fishman 2014). Others are of the view that the timing of transit should not rely on chronological age, but be based on the level of maturity and responsibilities of each patient (Gilliam *et al.* 2011, O'Sullivan-Oliveira *et al.* 2014, de Silva & Fishman 2014).

Five studies examined the age of patient transitioned to adult care services. Of the five studies, four indicated that transition occurred between the ages of 18, or after graduating from high school, to 19 years (Huang *et al.* 2011, Garvey *et al.* 2012, Godbout *et al.* 2012, Sebastian *et al.* 2012). The remaining study reported greater delays with patients in their early twenties (Fortuna *et al.* 2012).

Category 2 Perceptions of the transitions

Twenty-eight included studies investigated the perceptions of patients, parents and health care providers towards the transition process.

From patients' perspective, 13 studies examined their pre-transition perceptions. Patients expressed negative feelings towards the idea of transition. They felt anxious about the thought of the upcoming transition (Valenzuela *et al.* 2011, Chaudhary *et al.* 2013, Rutishauser *et al.* 2014, Thomson *et al.* 2014) or were unwilling to be transitioned (Bryant *et al.* 2011) because they were uncertain or concerned about the process (Bryant *et al.* 2011, Godbout *et al.* 2012, Applebaum *et al.* 2013, Swift *et al.* 2013, de Silva & Fishman 2014). In particular, patients were worried if they would be accepted by the adult care services (Swift *et al.* 2013, Stewart *et al.* 2014). However, in three other studies, patients verbalised they were ready and keen to transit (Wong *et al.* 2010, van Staa *et al.* 2011b, Dickinson & Blamires 2013).

Patients, after transit to the adult care services, acknowledged challenges and considerable differences between the

Table 1 Characteristics of the 61 included studies

First author (year) country of origin	Health condition	Study design	Data collection method	Sample	Main results – six categories						
					Timing of transition	Perceptions of the transition	Preparation for the transition	Outcomes post- transition	Barriers	Facilitating factors	
Blackman (2014) USA	Cerebral palsy (CP)	Quantitative	Survey	80 AYACD (15–17 years)	✓						
de Silva (2014) USA	Inflammatory bowel disease	Literature review	Search was not reported	31 articles (1999–2013)	✓	✓		✓	✓	✓	✓
Fernandes (2014) USA	Chronic disease	Quantitative	Survey	155 AYACD (16–25 years) 104 parents	✓				✓	✓	
Huang (2014) USA	Chronic disease	Quantitative	RCT	81 AYACD (12–20 years)	✓	✓			✓	✓	✓
Knapp (2014) The Netherlands	Chronic disease	Quantitative	Survey	376 matched pairs of adolescent (≥16) -parent	✓	✓		✓			
McLaughlin (2014) USA	Chronic disease	Quantitative	Survey	169 Internists 195 GPs	✓	✓					
O'Sullivan- Oliveria (2014) USA	Chronic disease	Qualitative	Four focus groups	28 HCPs	✓					✓	
Rutishauser (2014) Switzerland	Chronic disease	Quantitative cross-sectional	Survey	AYACD 283 pre-transfer 89 post-transfer	✓	✓				✓	✓
Shrewsbury (2014) Australia	Obesity	Systematic review	Search 1982–2012	Three primary-documents and 24 2nd documents						✓	
Stewart (2014) Canada	Disability	Qualitative phenomenological study	Individual and focus group interview	57 in total 15 AYACD (19–30 years); 16 parents; 25 HCPs; seven researchers				✓			✓
Thomson (2014) Canada	Epilepsy	Systematic review	Search 1994–2014 (12–25 years patients)	54 included studies		✓					
van Staa (2014) USA	Chronic disease	Quantitative	Survey	518 AYACD (18–25 years)		✓			✓		
Zhang (2014) Australia	Chronic disease	Literature review	Search was not reported	31 articles published from 1999–2013					✓		
Applebaum (2013) USA	Rheumatology and general	Mixed methods	Survey & focus group	AYACD (13–21 years) 35 survey 20 AYACD +13 parents interview		✓			✓		
Baumann (2013) Switzerland	Neuro- disabilities	Quantitative	Chart review	267 AYACD (16–25 years)						✓	

Table 1 (continued)

First author (year) country of origin	Health condition	Study design	Data collection method	Sample	Main results – six categories					
					Timing of transition	Perceptions of the transition	Preparation for the transition	Outcomes post- transition	Barriers	Facilitating factors
Bindels-de Heus (2013) The Netherlands	Profound intellectual & multiple disabilities	Quantitative	Survey	131/583 parents of AYACD with PIMD (16–26 years)	✓	✓	✓	✓	✓	✓
Chaudhary <i>et al.</i> (2013) USA	Cystic fibrosis	Quantitative	Survey	91 adult CF AYACD mean age 30.8 ± 9.3	✓	✓	✓	✓	✓	✓
Dickinson (2013) New Zealand	Juvenile idiopathic Arthritis (JIA)	Qualitative	Focus groups	Eight AYACD with JIA (16–21 years)	✓	✓	✓	✓	✓	✓
Garvey (2013) USA	Type 1 diabetes	Quantitative	Survey	65 Respondents (response rate 32%) mean age 26.6 ± 3.0	✓	✓	✓	✓	✓	✓
Hilderson (2013) Belgium	JIA	Qualitative	Semi-structured in-depth interview	11 AYACD (18–30 years)	✓	✓	✓	✓	✓	✓
Hunt (2013) USA	Chronic disease	Quantitative	Survey	179/11,218 Adult-centered hospitalists responded	✓	✓	✓	✓	✓	✓
McManus (2013) USA	Chronic disease	Quantitative	Survey	17,114 parents respondents of AYACD (12–18)	✓	✓	✓	✓	✓	✓
Paul (2013) UK	Mental health	Quantitative	Survey	154 AYACD mean age 18.1 (SD = 0.8)	✓	✓	✓	✓	✓	✓
Schwartz (2013) USA	Cancer	Mixed methods	Survey & focus groups	14 AYACD (16–28 years) Parents (<i>n</i> = 18) HCPs (<i>n</i> = 10)	✓	✓	✓	✓	✓	✓
Sonneveld (2013) The Netherlands	JRA; Type 1 diabetes; neuro- muscular disorder	Quantitative	Survey	127 AYACD (12–25); 166 parents; 18 HCPs	✓	✓	✓	✓	✓	✓
Stinson (2013) Canada	Chronic disease	Systematic review	Search period (1995–2012)	14 Included studies	✓	✓	✓	✓	✓	✓
Swift (2013) UK	ADHD – mental health	Qualitative	Semi-structured interview	Parents and 10 ADHD patients aged ≥17 years	✓	✓	✓	✓	✓	✓
van der Toorn (2013) The Netherlands	Chronic urological condition	Quantitative	Survey	80 AYACD (mean age 21) seven parents	✓	✓	✓	✓	✓	✓

Table 1 (continued)

Main results – six categories												
First author (year) country of origin	Health condition	Study design	Data collection method	Sample	Timing of transition	Perceptions of the transition		Outcomes				
						transition	transition	post-transition	transition	Barriers	Facilitating factors	
Collins (2012) USA	Chronic disease	Quantitative	Survey	113 Paediatric HCPs								
Fortuna (2012) USA	Chronic disease	Quantitative	Survey	Cross-sectional data of two national survey – AYACD (22–30 years) delayed transition								
Garvey (2012) USA	Type 1 diabetes	Quantitative	Survey	258 (53%) AYACD mean age 19.5 ± 2.9								
Godbout (2012) France	Chronic endocrine conditions	Quantitative	Survey	73/153 AYACD mean age 24.7 ± 4.5								
Hankins (2012) USA	Sickle cell disease (SCD)	Quantitative	Pre-post measures	83 AYACD (17–19 years)								
Helgeson (2012) USA	Type 1 diabetes	Quantitative	Survey	118 AYACD mean age 18.05(SD = 0.36)								
Hovish (2012) UK	Chronic disease	Mixed methods	Case note review & interview	11 AYACD (no age provided); six parents; three clinicians in CCS; six Clinicians in ACS								
Pakdeeprom (2012) Thailand	Chronic disease	Quantitative	Survey	100 AYACD (14–20 years)								
Sebastian (2012) UK	Inflammatory bowel syndrome (IBS)	Quantitative	Survey	Gastroenterologists								
Bhaumik (2011) UK	Intellectual disability	Mixed methods	Mapping; survey; grounded theory – interview	358/729 (62%) adult & 82/132 (49%) paediatrics								
Brewer (2011) USA	Disabilities	Quantitative	Pre-post programme	Mapping/informants from three services; survey – carers of AYACD 79/140 (56%); interview – 24 Carers								
Bryant (2011) USA	Haemoglobinopathy	Qualitative phenomenological study	Semi-structured interview	14,733 AYACD average age: 17.6								
				14 AYACD (19–15 years)								

Table 1 (continued)

First author (year) country of origin	Health condition	Study design	Data collection method	Sample	Main results – six categories							
					Timing of transition	Perceptions of the transition	Preparation for the transition	Outcomes post- transition	Barriers	Facilitating factors		
Croke (2011) USA	Disabilities	Mixed methods	Survey data; observations; & semi-structured interview	403 AYACD (15–18 years); Sample size not reported for qualitative data collection								
Davies (2011) Canada	Neurological disorder	Qualitative	In-depth interview	17 Parents of 11 AYACD (18–21 years)								
Dowshen (2011) USA	HIV/AIDS	Review	Search was not reported	Five studies								
Duke (2011) USA	Chronic disease	Quantitative	National Survey	18,198 Parents of AYACD (12–17 years)								
Dupuis (2011) Canada	Cystic fibrosis	Qualitative	Semi-structured Interview	26 participants seven families (seven AYACD, seven mums and four dads); Aged 15–18 years; eight HCPs								
Gilliam (2011) USA	HIV	Qualitative	Semi-structured face-2- face & phone interview	19 key informants/HCPs from 14 Adolescent Trials Network Clinics								
Goossens (2011) Belgium	Congenital heart disease	Quantitative	Observations & database	749 Patients with CHD ≥21 in 2009								
Huang (2011) USA	Chronic disease	Qualitative	Focus group	10 young adults (three IBD; four diabetes; three CF) & 24 HCPs								
Kaehne (2011) UK	Intellectual disabilities	Qualitative	Semi-structured interview	Three local authorities								
Kingsnorth (2011) Canada	Complex disability	Mixed methods	11 fields notes & focus group	30 participants for 11 peer support session; eight Parents of AYACD (12–18 years)								
Maslow (2011) USA	Chronic disease (CD)	Quantitative	Data from a national survey	13,136 non-CD 829 with CD mean age 28.8								
Nishikawa (2011) USA	Chronic disease	Quantitative	Data from a national survey	18,198 AYACD (12–17 years)								
Park (2011) USA	Chronic disease	Quantitative	Review document and database	Framework and researches; National survey data								

Table 1 (continued)

First author (year) country of origin	Health condition	Study design	Data collection method	Sample	Main results – six categories					
					Timing of transition	Perceptions of the transition	Preparation for the transition	Outcomes post- transition	Barriers	Facilitating factors
Price (2011) UK	Type 1 diabetes	Qualitative	Semi-structured interview	11 AYACD & two returned after a year for a 2nd interview	✓	✓	✓	✓	✓	✓
Sawicki (2011) USA	Chronic disease	Quantitative	Survey	192 AYACD (16–26 years)			✓			
Valenzuela (2011) USA	HIV	Qualitative	Semi-structured interview	10 HIV from AYACD (24–29 years)		✓				
van Staa (2011a) The Netherlands	Chronic disease	Qualitative	Semi-structured interview	24 AYACD after transfer (15–22 years) 24 parents; 17 HCPs		✓			✓	
van Staa (2011b) Netherlands	Chronic disease	Quantitative	Survey	954/3,648 AYACD completed (12–19 years)			✓			
de Beaufort (2010) Canada	Diabetes	Quantitative	Survey	92/578 (16% of the International Society for Paediatric and Adolescent Diabetes)	✓		✓			
Fredericks (2010) USA	Liver transplant recipients	Quantitative	Survey	71 liver transplant recipient (11–20 years) & 58 parents			✓			
Wong (2010) Hong Kong	Chronic disease	Quantitative	Survey	137 AYACD (16–19 years) 67 parents		✓			✓	✓

two health care services with regard to environment and care delivery (Price *et al.* 2011, Valenzuela *et al.* 2011, Hilderson *et al.* 2013, Huang *et al.* 2014, de Silva & Fishman 2014, Van Staa & Sattoe 2014). In general, some patients felt satisfied with the transition process (Bhaumik *et al.* 2011, Price *et al.* 2011, Godbout *et al.* 2012, Chaudhary *et al.* 2013, Sonneveld *et al.* 2013) and considered the transition as an opportunity for individual growth (van Staa *et al.* 2011a, Valenzuela *et al.* 2011). Other patients were less satisfied with the transition process, and they even felt pushed into the adult care service (Bhaumik *et al.* 2011, Bryant *et al.* 2011, de Silva & Fishman 2014) without sufficient preparation (Blackman & Conaway 2014, Van Staa & Sattoe 2014).

For parents/carers, leaving paediatric care services was more challenging than for patients (van Staa *et al.* 2011a). Prior to the transition, parents/primary carers indicated concerns about the process (Kingsnorth *et al.* 2011, Swift *et al.* 2013). They also felt stressed about the future, and this was over and above the ongoing suffering of living with their child (Dupuis *et al.* 2011, Kingsnorth *et al.* 2011). Parents were also worried about being labelled as over-advocating or being 'difficult' in the transition process. Only limited evidence revealed positive feelings of the parents towards the transition and this related to their awareness of the transition plan (Wong *et al.* 2010, Knapp *et al.* 2014).

Only one study explored parental perceptions on their child's transition process. Parents expressed their feeling of being abandoned and lost during the transition process. They were also fearful in navigating adult care services (Davies *et al.* 2011).

In terms of how health care providers perceived the transition process variations were evident between paediatric and adult services. Adult health care providers considered paediatric service providers were over protective; whereas adult health care providers were perceived as uncaring towards the adolescent and young adult patients by paediatric health care providers (de Silva & Fishman 2014). Also, 40% of adult health care providers felt uncomfortable caring for the young adult patients (Hunt & Sharma 2013). Further half of them were unwilling or not keen to accept the young adult patients (McLaughlin *et al.* 2014).

Category 3 Preparation for the transition

It has been recognised that preparing the adolescent and young adult patients for transition impacts significantly on patients outcomes post-transition (Bindels-de Heus *et al.* 2013, Dickinson & Blamires 2013). It is essential, therefore, to assess the patients' readiness for the transit.

However, no single assessment tool/instrument has been widely accepted as the most reliable tool (de Silva & Fishman 2014).

A systematic review conducted by (Stinson *et al.* 2013) focused on the transition readiness assessment instruments/tools and concluded that the tools from the eight included studies were neither reliable nor valid, including Transition Readiness Assessment Questionnaire (TRAQ). In a more recent review, ten transition readiness assessment tools were examined with a focus on the psychometric properties of the tool. The review argued that TRAQ demonstrated adequate content validity, construct validity, and internal consistency. As a result TRAQ was recommended as the best-validated tool to assess the adolescents and young adults' readiness for the transition (Zhang *et al.* 2014).

In other research, Schwartz *et al.* (2013) identified that the Social-Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) proved to be a valid tool. The reliability was supported by other studies that examined the four-specific components disease-related knowledge (Fredericks *et al.* 2010, van der Toorn *et al.* 2013), skills/self-efficacy (Fredericks *et al.* 2010, Sawicki *et al.* 2011, van Staa *et al.* 2011b, Applebaum *et al.* 2013, van der Toorn *et al.* 2013), relationships/communication (van der Toorn *et al.* 2013), and psychosocial/emotions (Fredericks *et al.* 2010). The SMART measured the patients' beliefs/expectations, developmental maturity (patient only), goals/motivation to determine if the patients are ready to be transferred to the adult care service (Schwartz *et al.* 2013).

Additional characteristics also identified as impacting the quality of the preparation process include gender (Fredericks *et al.* 2010, Sawicki *et al.* 2011, McManus *et al.* 2013), age (Fredericks *et al.* 2010, Sawicki *et al.* 2011, McManus *et al.* 2013, Knapp *et al.* 2014), ethnicity group (McManus *et al.* 2013), family annual income (McManus *et al.* 2013), severity of the illness (Sawicki *et al.* 2011, McManus *et al.* 2013), level of psychosocial support (Pakdeeprom *et al.* 2012), patients' attitude towards transition (van Staa *et al.* 2011b, Pakdeeprom *et al.* 2012), source and type of paediatric care (Duke & Scal 2011), and health insurance access (Fortuna *et al.* 2012, McManus *et al.* 2013).

Category 4 Patients' outcomes post-transition

Five included studies evaluated the effectiveness of transition programmes. In general, patients valued the structure and guidance offered by the programmes, especially those that assisted patients to gain independence socially and physically (Chaudhary *et al.* 2013, Huang *et al.* 2014), to

comply with adult clinic visits (Hankins *et al.* 2012), and to engage in career development activities (Brewer *et al.* 2011, Croke & Thompson 2011). Patients also appreciated being informed about drugs and alcohol prevention and meeting adult health care providers prior to transition (Price *et al.* 2011). However, regardless of the implemented available transition programmes, patients' anxiety levels towards the transition did not alter (Chaudhary *et al.* 2013).

Sixteen studies measured the outcomes of the patients who had not been involved in a structured transition program. There was no systematic evaluation of the outcomes mainly due to the lack of tracking mechanisms for transferred patients (Gilliam *et al.* 2011). The transition record was often incomplete, so the total number of reported transitions was based on estimation (Bhaumik *et al.* 2011, Gilliam *et al.* 2011). Patients articulated that the care they received post-transition was inconsistent and of a less standard compared to the paediatric setting (Bhaumik *et al.* 2011, Goossens *et al.* 2011, Park *et al.* 2011, van Staa *et al.* 2011a, Helgeson *et al.* 2012, Paul *et al.* 2013, Sonneveld *et al.* 2013). This was evidenced by poor medication adherence (van Staa *et al.* 2011a, de Silva & Fishman 2014) and low clinic attendance or even cessation of follow-up appointments (Goossens *et al.* 2011, van Staa *et al.* 2011a, Helgeson *et al.* 2012, de Silva & Fishman 2014). Also, two studies examined the social outcomes of patients compared to those without chronic health conditions. Patients with chronic illnesses/disabilities experienced poor educational and vocational opportunities with low graduating rates from college and lower incomes (Maslow *et al.* 2011, Baumann *et al.* 2013).

Despite the lack of structured transition programmes, four studies reported positive patient outcomes a year or more after being transitioned. These included general satisfaction with care provision (Dickinson & Blamires 2013), treatment (Godbout *et al.* 2012) and advice on their future life (Nishikawa *et al.* 2011). One study also reported that patients had similar rates of marriage and having children as when compared to those without childhood illness (Maslow *et al.* 2011).

Category 5 Barriers to the transition

Five major barriers were identified as impacting the transition process. The first barrier related to inadequate preparation prior to transition. Patients reported not being referred to a specific adult HCP (Garvey *et al.* 2013), not receiving information from an adult HCP (Wong *et al.* 2010, Kaehne 2011, Garvey *et al.* 2012, Paul *et al.* 2013, Rutishauser *et al.* 2014, de Silva & Fishman 2014), not being offered a

visit prior to transition to the adult care service (Garvey *et al.* 2012, Hilderson *et al.* 2013), and poor communication between the health care providers (Wong *et al.* 2010, Kaehne 2011, Garvey *et al.* 2012, de Silva & Fishman 2014). Patients also reported a lack of satisfaction with the transition process due to unavailability of structured written-plans (Bhaumik *et al.* 2011, Gilliam *et al.* 2011, Kaehne 2011, van Staa *et al.* 2011a, Shrewsbury *et al.* 2014) and the lack of coordination of the process (Bhaumik *et al.* 2011, Davies *et al.* 2011, Huang *et al.* 2011, Kaehne 2011, Paul *et al.* 2013, Sonneveld *et al.* 2013).

Ability to access and use adult care services was considered as the second major barrier. Issues include lack of resources (Bhaumik *et al.* 2011, Davies *et al.* 2011, Gilliam *et al.* 2011, Huang *et al.* 2011, Collins *et al.* 2012, Godbout *et al.* 2012, Sebastian *et al.* 2012, Paul *et al.* 2013, O'Sullivan-Oliveira *et al.* 2014, Stewart *et al.* 2014), limited availability of the clinicians' time (Bhaumik *et al.* 2011, Collins *et al.* 2012, Sebastian *et al.* 2012), limited health insurance coverage (Dowshen & D'Angelo 2011, Gilliam *et al.* 2011, Huang *et al.* 2011), long waiting lists (Hovish *et al.* 2012), and lack of a tracking mechanism after patients are transitioned (Gilliam *et al.* 2011). Inconsistencies in the provision of care to patients were also considered as a limitation. This was seen as resulting from the different model of care delivered in the adult care setting as compared to the paediatric setting (Huang *et al.* 2011, Garvey *et al.* 2012, 2013, Hovish *et al.* 2012). Specifically, insufficient communication, especially handing over patients' information from paediatric to adult health service providers were identified (Dowshen & D'Angelo 2011, Gilliam *et al.* 2011, Huang *et al.* 2014, de Silva & Fishman 2014, Stewart *et al.* 2014).

Complex health conditions posed the third barrier to the transition process. The transition was impacted according to health service providers by patients' impaired cognitive development and mental health issues (Davies *et al.* 2011, Gilliam *et al.* 2011, van der Toorn *et al.* 2013). Other issues included patients' negative attitude towards the transition (Wong *et al.* 2010, Gilliam *et al.* 2011, Rutishauser *et al.* 2014, de Silva & Fishman 2014), difficulties leaving a familiar environment (Dowshen & D'Angelo 2011, van der Toorn *et al.* 2013, Fernandes *et al.* 2014, O'Sullivan-Oliveira *et al.* 2014, Rutishauser *et al.* 2014), insufficient knowledge and self-management skills (Gilliam *et al.* 2011, Sonneveld *et al.* 2013, de Silva & Fishman 2014) and especially poor medication and follow-up adherence (Gilliam *et al.* 2011, van der Toorn *et al.* 2013).

Excessive parental involvement in the care of patients was perceived as the fourth barrier to the transition by both

nurses and physicians (Huang *et al.* 2011, de Silva & Fishman 2014). This was evidenced by parents' negative attitude towards adult care services (Wong *et al.* 2010, O'Sullivan-Oliveira *et al.* 2014), over controlling of their child (Huang *et al.* 2011, Sonneveld *et al.* 2013, de Silva & Fishman 2014), and over-reliance on the paediatrician (Bindels-de Heus *et al.* 2013, van der Toorn *et al.* 2013, Fernandes *et al.* 2014, de Silva & Fishman 2014).

The final barrier involves the inability of some paediatric health care providers to relinquish care of the patient (Dowshen & D'Angelo 2011, de Silva & Fishman 2014). Paediatric health care providers found it difficult to hand over patients to the adult care services due to long-established rapport with patients and their families (Gilliam *et al.* 2011, O'Sullivan-Oliveira *et al.* 2014). In contrast, adult health care providers faced challenges relating to non-familiarity with the treatment and clinical parameters of the patients (Dupuis *et al.* 2011, Huang *et al.* 2011, Hunt & Sharma 2013, Stewart *et al.* 2014).

Category 6 Facilitating factors to the transition

Nine included studies explored factors that enable the transition process. Facilitating factors include preparation prior to transit (Wong *et al.* 2010, Hovish *et al.* 2012), a structured written plan/program to guide the transition process (Gilliam *et al.* 2011, Hovish *et al.* 2012, Sebastian *et al.* 2012), a key health care provider from paediatric care services to coordinate the transition process (Collins *et al.* 2012, Hovish *et al.* 2012), the quality of health care providers and relationship built-up with the patients (Wong *et al.* 2010, Swift *et al.* 2013), parents acting as a facilitator (Davies *et al.* 2011, Kingsnorth *et al.* 2011, van der Toorn *et al.* 2013), and patients' self-management skills (Wong *et al.* 2010, de Silva & Fishman 2014).

Discussion

We conducted this integrative review to synthesise the research evidence from 2010–2014 on transitions of care for the adolescents and young adults with chronic illnesses/disabilities. This integrative review adds to the body of knowledge of 16 previous review papers published ≤2010 (Refers to Table 2).

Congruent evidence was found in this review that patients should be made aware they will need to transition to adult services. The ideal timing to transit patients to adult care services broadly ranged from the late teens to the early twenties. It was argued that patients should be transitioned according to their developmental stage and self-management abilities, which is similar to three prior review

papers (While *et al.* 2004, Jalkut & Allen 2009, Fegran *et al.* 2014). In reality, however, patients were mostly transitioned in their late teens, especially at the 'iconic' age of high school graduation (Watson *et al.* 2011, Hanna & Woodward 2013).

The majority of patients in this review expressed negative feelings towards transition, which was consistent with four previous review papers (Jalkut & Allen 2009, Wang *et al.* 2010, Hanna & Woodward 2013, Fegran *et al.* 2014). Some patients were even apprehensive about their future when surrounded by older and sicker patients (Lugasi *et al.* 2011). Consistent evidence from this and a previous review (Lugasi *et al.* 2011) suggests that parents/carers felt reluctant towards the transition with general concern expressed about the process and feelings of abandonment. Health care providers with adolescent care experience considered the transition as part of their routine practice while others with only adult care experience felt uncomfortable to care for adolescent and young adults. Paediatric health care providers, however, displayed a lack of trust in adult health care providers by being unwilling to hand over care of the patients (Jalkut & Allen 2009).

Evidence from this review indicates there has been an increased effort to prepare patients prior to transition by assessing readiness, which was not formally recognised in any of the previous review papers. However, inconclusive evidence was found on the effectiveness of transition readiness assessment tool.

This review compared to the seven previous reviews found that most 'programs' identified in the literature were approaches or services, and not formally structured transition programs. The main content of the approaches or services from previous reviews included (1) introduction of transition coordinator; (2) self-management skill training; (3) flexibility of adult clinic service delivery; and (4) assessment of readiness (Kingsnorth *et al.* 2007, Crowley *et al.* 2011, de Jongh *et al.* 2012, Hanna & Woodward 2013). It was noticed that most approaches/services developed were for specific health conditions, i.e., cystic fibrosis (Doug *et al.* 2011), diabetes (Crowley *et al.* 2011, Hanna & Woodward 2013), and physical disabilities (Kingsnorth *et al.* 2007) rather than for more generic use. Four studies argued that patients with health conditions, such as HIV/AIDS, severe intellectual disability and obesity, received very little attention when transitioning from paediatric to adult health services (Dowshen & D'Angelo 2011, Gilliam *et al.* 2011, Maslow *et al.* 2011, Shrewsbury *et al.* 2014).

Also, Grant and Pan (2011) analysed five structured transitioning programmes for the young adult population

Table 2 Characteristics of the 16 previously published review articles

First author (year) country of origin	Health condition	Study design	Search period	Included studies	Main results – six categories					
					Timing of transition	Perceptions of the transition	Preparation for the transition	Outcomes post-transition	Barriers	Facilitating factors
Fegran (2014) Denmark	Chronic disease	Qualitative meta-synthesis	1999 – November 2010	18 studies	✓	✓				
Hanna (2013) USA	Diabetes	Systematic review meta-analysis	Not reported	23 studies published from 1992–2012	✓	✓		✓		
Bloom (2012) USA	Chronic disease	Literature review	1986–2010	15 studies				✓		
de Jongh (2012) UK	Chronic disease	Systematic review meta-analysis	1993–2009	Four RCTs included				✓		
Crowley (2011) UK	Chronic disease	Literature review	1998–2010	10 studies				✓		
Doug (2011) UK	Palliative care	Literature review	1995–February 2008	92 studies				✓		
Grant (2011) Canada	Chronic disease	Content analysis	Not reported	Five transition models				✓		
Lindsay (2011) Canada	Chronic disease	Integrative review	2000 – August 2010	34 studies					✓	
Lugasi (2011) Canada	Chronic disease	Meta-summary review	1994–2009	46 studies		✓		✓	✓	✓
Watson (2011) UK	Complex healthcare needs	Scoping review	Not reported	19 studies published from 1990–2010	✓					
Main results – eight categories										
First author (year) country of origin	Health condition	Study design	Search period	Included studies	Timing of transition	Perceptions of the transition	Preparation for the transition	Outcomes post-transition	Barriers	Facilitating factors
Lonstein (2010) USA	Chronic disease	Literature review	Not reported	33 studies published from 1990–2010					✓	
Rapley (2010) Australia	Chronic disease	Integrative review	Not reported	74 Studies published from 1989–2008						✓
Wang (2010) USA	Chronic disease	Literature review – an ecological approach	1999–2008	46 studies		✓			✓	
Jalkut (2009) USA	Congenital heart disease	Literature review	1950–2008	28 studies	✓	✓				
Kingsnorth (2007) Canada	Physical disabilities	Systematic review	1985–2006	Six studies				✓		
White (2004) UK	Chronic disease	Literature review	1981–2001	126 studies	✓					✓

with chronic illnesses/disabilities. Overall, the appraised intervention/services and programmes were found to be useful, especially for diabetic patients trying to maintain glycosylated haemoglobin levels (Crowley *et al.* 2011, Hanna & Woodward 2013). However, the validation and sustainability of most of the intervention and programs were questioned (Kingsnorth *et al.* 2007, Doug *et al.* 2011, Grant & Pan 2011, Watson *et al.* 2011, de Jongh *et al.* 2012, Hanna & Woodward 2013). There is limited evidence on developing and implementing transitioning programmes for young adults with complex health needs, such as cerebral palsy and autism (Watson *et al.* 2011).

The review also found poor patients' outcomes both clinically and psychosocially after being transitioned without structured transition programmes, which was supported by two previous review papers (Lugasi *et al.* 2011, Bloom *et al.* 2012, Hanna & Woodward 2013). Some patients articulated that they were treated like adults being part of decision-making and taking more control of their health conditions (Lugasi *et al.* 2011).

Both this review and five previous reviews agreed on five major barriers hindering the transition process, including lack of planned transition process, insufficient preparations, poor health care service accessibility, ineffective communication between health care services and a negative attitude by patients towards the transition process (Jalkut & Allen 2009, Lotstein *et al.* 2010, Wang *et al.* 2010, Lindsay *et al.* 2011, Lugasi *et al.* 2011).

Facilitating factors associated with a smooth transitioning process were identified by four earlier review studies and were consistent with the outcomes of this review. Patients and their carers appreciated gradual preparation following a structured transition programme, consistency of care, high quality of adult health care providers, parental support, and the patients taking responsibilities of their own health (While *et al.* 2004, Rapley & Davidson 2010, Lugasi *et al.* 2011).

The limitation of this integrative review is associated with the search strategy which might have excluded relevant non-English research studies. The main weakness of the included studies in this integrative review was the lack of objective data resulting from compromises made to research design. More than half of the included studies (32/61) was nonexperimental self-report surveys. Only two out of 15 included qualitative studies specified the methodology and underlining philosophy being employed – phenomenological theory.

An integrated, rigorous research approach including both quantitative and qualitative methods to examine effectiveness of the transition programme is urgently recommended.

Due to inconclusive evidence, further validation of the two identified transition readiness assessment tools (SMART vs. TRAQ) is needed. Most importantly, inconsistent outcomes measures need to be addressed to improve the quality of patients' transitioning experience.

Conclusion

In the last five years, there has been improved health outcomes for adolescents and young adults with chronic illnesses/disabilities post-transition through the use of a structured multidisciplinary transition programme, especially for patients with cystic fibrosis and diabetes. However, overall patient outcomes following the transit, if recorded, have remained poor both physically and psychosocially. Active preparation for transitioning paediatric patients with ongoing special health care needs should commence in their early teens. Parents/primary carers, paediatric health care providers, and the receiving adult health care providers also needed to be included in the preparation. Patients' readiness for transition needs to be accurately and regularly assessed by applying validated measurement tools. The priority for stakeholders and health care providers for both paediatric and adult services is to develop a standardised and evidence-based transition program, which must be user-friendly to all patients rather than condition specific. The information with regard to patients' diagnosis, investigation, management plan, and family/social background is required to be communicated and shared by the health care providers. Training programs also need to be organised for adult health care providers to improve their medical knowledge and communication skills. This review also strongly recommends the need for accurate tracking mechanism to be established by health care services to monitor patients' outcomes post-transition, which will ultimately improve the transitioning care for adolescents and young adults with chronic illnesses/disabilities.

Contributions

Study design: HZ & PD; Data collection and analysis: HZ, PD, PR & SD; and manuscript preparation: HZ, PR, PD & SD.

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